

Developing a model for peer support for patients with lung cancer

Final Report
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Introduction

Lung cancer is now the biggest cause of death due to cancer in the world. In Victoria, lung cancer is the leading cause of death due to cancer in men and the second leading cause in women after breast cancer. This reflects the fact that to date, the long-term results of treatments are poor, with only 15% of patients alive 5 years post-diagnosis. Few early warning symptoms occur; hence presentation usually occurs when the disease is advanced, with median survival times of 9-12 months. Symptoms frequently include pain, breathlessness, cough, weight loss and fatigue. These symptoms have been shown to result in significant impairment of psychological well-being and need for support by both patients and their carers.

Studies that have screened patients with lung cancer for evidence of psychological distress have reported rates between 15 and 69%, with carers of patients with advanced cancer frequently also reporting substantial psychological distress warranting specific support. However, it is known that both psychosocial and other causes of distress frequently go undetected - which can contribute to worse patient quality of life and poorer outcomes including treatment compliance rates.

The aim of this project was to assess the support needs of patients with lung cancer in Victoria and develop an appropriate model(s) for delivering peer and other types of support to this group of patients. The following report outlines the work done as part of this project to meet the planned study objectives.

Project Objectives

1. Objective 1 - Determine the general and unique support needs of patients with lung cancer in Victoria and their carers

To determine the support needs of people with lung cancer in Victoria and their carers, the following was completed.

1. Systematic review of the literature to identify the support needs of people affected by lung cancer (complete)
2. Systematic review of the literature to identify any interventions which have been developed to meet the support needs of people affected by lung cancer and their carers (complete)
3. Supportive Care Screening Tool Data Analyses
Analyses of data available for lung cancer patients who have completed the Supportive Care Screening Tool developed at Peter Mac (complete).

Review of the available literature to date demonstrated that multiple unmet needs for support have been described in patients with lung cancer and their carers. However, the majority of the literature is descriptive and very few interventions designed to meet these needs have been developed or rigorously evaluated. The needs identified are grouped within the table below

DOMAINS	AREAS OF NEED
Physical concerns	Symptoms of the disease and its treatment Level of physical function Age-related concerns
Emotional and Psychological concerns	Psychological distress Quality of life Shame, stigma and social isolation related to having a smoking-related illness Living with cancer and the impact of varying coping strategies
Informational and Communication concerns	Concerns of newly diagnosed patients Communication concerns Information needs
Family and caregiver concerns	Family and caregiver needs Communication concerns Living with cancer in the family
Spiritual concerns	Spirituality Existential concerns Facing death
Needs for practical help	Finances Assistance with activities of daily living Assistance with transport, parking and accommodation

Review of the experience of screening for supportive care needs in lung cancer patients at the Peter MacCallum Cancer Centre also demonstrated very high levels of unmet needs for support. It was demonstrated that the use of the screening tool in everyday

clinical practice is feasible and results in the majority of patients being referred for additional supportive care (see *Abstract in Appendix 1*).

2. Objective 2 - Determine the reasons why existing support services are under-utilized by patients with lung cancer and their carers.

Prior to determining the reasons why existing support services are under-utilized we needed to identify what services were currently available for people affected by lung cancer within Victoria

To find out what support services were developed, available and readily accessible within Victoria the project team met with both clinicians and organisations working directly with people affected by lung cancer and asked what support services they were aware of and utilized. We contacted the following clinicians / organisations:

- Lung Cancer Nurse Co-ordinator at PeterMac
- The Cancer Council Victoria (TCCV) Support Group Co-ordinator
- Members of the Victorian Cooperative Oncology Group: Lung Cancer committee
- Australian Lung Foundation (ALF)
- Clinicians and organisations represented at the Inaugural Lung Cancer Conference 2006.

As well a comprehensive web-based search was performed to identify any support services available and/or promoted on the internet.

Through this process we identified that Victoria had no support services or programs developed specifically for people affected by lung cancer, aside from one support group specifically for patients affected by mesothelioma. The TCCV offered general support groups and services for people affected by cancer (eg. Cancer helpline, Cancer Connect). However, none of these services were specifically for lung cancer, and there tended to be very poor uptake by lung cancer patients. A number of internet support programs were found, however these were not Australian based. The internet had a number of sites that provided information for patients and families regarding lung cancer however, again with one exception, these were not Australian based. (See *appendix 2 – existing support services for people affected by lung cancer*)

We also wanted to determine if people affected by lung cancer did attend the general cancer support groups that were operating in the community. The project team developed a questionnaire which was sent to all facilitators of TCCV affiliated cancer support programs (see objective 3 for further details of the facilitator questionnaire). 53% of those sent a survey responded, with many non-responders indicating that their support group was specific for another cancer type eg. breast. Out of the 75 facilitators who responded to this questionnaire 35% had experienced a lung cancer patient attend their program. Of this 35%, only 4 facilitators had experienced more that 1 person with lung cancer attend their support group. A large percentage of facilitators in this sample indicated the following were “somewhat or very much” barriers for people with lung cancer wanting to attend support programs:

- feeling too unwell
- too many health related problems
- not wanting to see people sicker than themselves

- not wanting to travel,
- parking and transport,
- not wanting to talk about their lung cancer

The work performed under objective 1 and 2 indicated that the support needs of lung cancer patients appear to be unique and not adequately provided for by the available services.

3. Objective 3 - Develop a model/s for providing support to patients with lung cancer

As indicated above we found no support programs available for people affected by lung cancer within Victoria. To enable us to develop a model of support for people affected by lung cancer we needed to identify what this group of people wanted from a support program as well as their likelihood of actually attending a program if it met their needs.

The project team developed two questionnaires - one for patients affected by lung cancer and one for facilitators of TCCV affiliated support groups.

Both questionnaires used the same framework and asked:

- what type of information/education/support would be useful in a lung cancer program
- what type of format would be most appropriate in a lung cancer support program
- what are the barriers for people with lung cancer attending a lung cancer support program
- would you attend a lung cancer support program if it suited your needs (patient questionnaire only)

A summary of the questionnaire results can be seen within the abstract in Appendix 3. These questionnaires were developed in conjunction with the “Models of Peer Support for Bowel Cancer” Group who have been identifying what patients with bowel cancer want in a support program, and have also performed some qualitative focus group work with patients. By collaborating together we have been able to compare and contrast the support needs of both patients groups - lung and bowel cancer – which in general appear to be similar.

Development and piloting of peer support program

The results of the questionnaires as well as the information gained from the systematic review provided us a framework for the development of a pilot lung support program.

The results from the patient questionnaire indicated that overall patients and their family/carers want information about all aspects of lung cancer and its treatments. In addition, they want to meet and talk to health professionals involved in caring for people with lung cancer. 89% of participants felt that meeting with health professionals involved in lung cancer care would be useful, whilst only 66% felt that meeting with people who had experienced lung cancer would be useful. This suggested that peer support may not be as important to this group as provision of information from health professionals. A large percentage (75.9%) of patients felt that they would like a health professional to run the program and the most preferred format was a small face to face group (48.1% said yes, 35.3 did not mind and only 13% said no to a small group). Facilitators also believe

that people with lung cancer want information about all aspects of lung cancer and felt a small group (73.8%) or one on one (81.2%) would be the most appropriate format.

Drawing on the results of the questionnaire, a pilot program for people affected by lung cancer and their carers was developed, which was information and education based. The TCCV assisted us in the development of this pilot program using their expertise and experience with support programs. The 4 session "Living with Cancer Program" was tailored to meet the needs of the lung cancer patient population. In each session we provided a large informational and educational component. In all 4 sessions guest speakers were invited to provide relevant education and information. These included health professionals from the lung cancer unit (medical oncologist, lung cancer nurse co-ordinator, dietician, physiotherapist, occupational therapist) as well as financial planners. The details of the pilot program are outlined in appendix 4.

4 Objective 4 – Pilot test the developed model with the lung cancer patients and their carers in metropolitan Melbourne

Prior to piloting the program, the nurse researcher identified eligible patients and approached them regarding attending this program.

Firstly the nurse researcher screened the Peter Mac Lung Cancer Unit treatment and clinic lists to identify patients that met the eligibility criteria.

The inclusion criteria included:

- having a newly confirmed (in the last 12 weeks) diagnosis of lung cancer - non-small cell lung cancer, small cell lung cancer or mesothelioma
- able to speak English
- clinical performance status ECOG ≤ 2
- 18 years or older
- Willing and able to attend the 4 weekly sessions

The exclusion criteria included:

- currently have an active psychiatric or cognitive disorder
- low clinical performance status ECOG >2 (and deemed not well enough to attend by treating clinicians)

There was a 6 week screening period preceding the pilot program.

In the screening period 47 patients were identified as having a newly diagnosed lung cancer. Out of these only 9 (19%) met the eligibility criteria. 12 patients (26%) did not speak english, 9 (19%) had ECOG >2 , 18 (38%) could not attend weekly sessions due to a number of reasons (in hospital -2, from country area – 12, not wanting to attend as having treatment elsewhere – 2, transport issues – 2). Some patients had more than one reason for not meeting eligibility criteria.

The nurse researcher approached the 9 eligible patients and explained the program and gave them a written invitation to attend the education and information sessions. 5 accepted the invitation.

The program was run over a 4 week period. Due to availability of the Financial Adviser guest speakers, session 4 was run prior to session 3.

The day prior to each session the nurse researcher contacted each participant to confirm their attendance at the program. On a number of occasions participants confirmed attendance however cancelled on the day. The following outlines attendance rates:

- Session 1 - 4 patients and 2 relatives attended (total 6 participants)
- Session 2 - 5 patients and 2 relatives attended (total 7)
- Session 3 – 2 patients and 1 relative (total 3)
- Session 4 – 2 patients (2 of the 5 participants attended the financial advice session, the others felt they did not require this information)

All the participants were interested in session 1, 2 and 3. However, a number of issues preventing them from attending including:

- Feeling too unwell
- Needing a rest from travelling into the hospital (having treatment most days)
- Having treatment at the time the program was running
- Having other family commitments (one patient needed to take his wife to another medical appointment)

Other Issues Identified

- Guest speakers felt it was difficult to justify the time needed to prepare and present the sessions as the participant numbers were small.
- As discussed above often participants cancelled their attendance on the day making it difficult to estimate how many patients would arrive.
- The specific needs of carers.

5 Objective 5 - Assess the efficacy of the pilot model with a view to expanding its availability to all people directly affected by lung cancer and their families, both in Victoria and throughout Australia.

Evaluation of Program

The participants completed an evaluation form. All participants were satisfied or very satisfied with the program. 3 participants noted they would have liked even more medical information regarding lung cancer.

In this small pilot it was demonstrated that patients and their family affected by lung cancer found education and information based program helpful. We plan to pilot a second program to see if we receive similar results.

The development and evaluation of the pilot program is the subject of a planned abstract submission to the Clinical Oncological Society of Australia (COSA) Annual Scientific Meeting.

Conclusions and ongoing development of program

To provide future support programs for patients with lung cancer and their carers we need to develop innovative ways to overcome the problems we identified, specifically providing sessions which patients can attend in a variety of formats as well as appropriate utilization of clinician time. It will also be important to address the needs of non-English speaking patients and the specific needs of carers

One initiative is to film relevant health professionals presenting information and education sessions to patients and their families affected by lung cancer. These would be made available in DVD/Blue Ray form and via the internet (on relevant lung cancer support sites such as the Australian Lung Foundation site). Patients and their family would be able to freely access these sessions in their own home, or in designated viewing areas in their treating hospitals/clinics, without needing to be well enough to attend a designated session. Peer support programs could be setup (face to face, on the telephone or over the internet) using these presentations as a basis for discussion. This would address the issue of clinician time as well as enabling patients and their families to access information when it is convenient.

Appendix 1

Supportive Care Screening Tool Abstract: Oral presentation at World Lung Cancer Conference, Seoul, 2007.

Screening for the Supportive Care Needs of Patients with Lung Cancer identifies high levels of unmet need

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Introduction: Lung cancer is a highly symptomatic disease resulting in frequent debility and psychosocial distress that may go undetected. Optimal care involves not only treatment of the disease but also the identification and management of supportive care needs.

Methods: The unit nurse coordinator assesses all new patients referred to the lung service at our hospital soon after their first initial consultation with a doctor. A detailed patient - completed screening tool has been designed to identify supportive care needs and prompt appropriate referrals within the lung team. We audited the results of 198 patients who completed the screening tool over the last 2 years.

Results: Patients reported high rates of concern about significant symptoms including pain (38%), dyspnoea (56%), fatigue (68%), nausea and vomiting (33%), bowel disturbance (28%) and weight loss (33%). Prominent needs for practical help included assistance with shopping (25%), financial assistance (35%) and transport to and from the hospital (33%). However, 18% of patients lived alone, 14% cared for dependents and 12% reported that no one was available to help. High needs for further information about treatments, side-effects, diet, complementary therapies and prognosis were identified in more than a third of patients. Many patients reported symptoms to suggest significant depression (40%) and anxiety (45%). Fifty percent felt that their usual social interactions with family and friends were moderately to extremely limited, and 25% reported that they had no one to talk to about their feelings and concerns. These findings resulted in the majority of patients requiring additional referral to medical and allied health staff.

Conclusions: Use of a screening tool in patients with lung cancer identifies high needs for additional supportive care to address symptoms, practical issues, information needs and psychosocial distress. Further research into the utility of interventions designed to meet these needs is required.

Appendix 2

Lung Cancer Resources: Results from Internet search in 2006

Support Programs /Information for patients and families affected by Lung Cancer

Within Victoria

Australian Lung Foundation (ALF)

- Provides a small amount of information about lung cancer, symptoms and treatment - written for patients and families

Web site: <http://www.lungnet.org.au/>

The Cancer Council of Victoria (TCCV)

Provides Support and Education:

- TCCV Cancer help line
- Cancer Connect
- Living with Cancer Education Programs
- Seminars for people planning to develop and facilitate support programs – can become a TCCV affiliated support program
- TCCV affiliated support groups for people with cancer – no lung cancer specific group identified
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Web site: <http://www.cancervic.org.au/>

Please note –The Cancer Council NSW provides a telephone support group specifically for lung cancer – N.S.W only

Web site: <http://www.cancerCouncil.com.au/>

Asbestos Diseases Society of Victoria

Provides support and education for people affected by mesothelioma

- Support group for people with mesothelioma

Web site: <http://www.adsvic.org.au/>

Outside Australia

Lung Cancer Alliance - USA

Provides support and education for people affected by lung cancer

- Information line - USA
- Phone Buddy Program - USA
- On Line and Face to Face Support Groups - USA
- Stories of hope

Web site: <http://www.lungcanceralliance.org/>

The Wellness Community - USA

Provides support and education for people affected by cancer

- On line and face to face support programs - USA

Web site: <http://www.thewellnesscommunity.org/>

The Lance Armstrong Organisation - USA

Provides education and support for people affected by cancer - USA

Web site: <http://www.livestrong.org/site/>

The Roy Castle Lung Cancer Foundation USA

Provides support and education for people affected by lung cancer

- Lung Cancer helpline - UK
- Monthly Support Groups -UK
- Stories of hope

Web site: <http://www.roycastle.org/patient/index.htm>

Other internet sites

Asbestosis Mesothelioma Information and Resource Guide - features common questions asked, articles, and list of physicians and healthcare centres treating mesothelioma and other asbestos related illnesses – USA based

Web site: <http://www.asbestosmesothelioma.com/>

Cancer Care - offers information for lung cancer patients and their families, as well as referral to CancerCare's free professional counselling, education programmes, and financial assistance for people with lung cancer – USA based

Web site: <http://www.lungcancer.org/>

Lung Cancer Online - offers information and resources for patients and families. Includes facts on symptoms, side effects, treatment options, and much more – USA based

Web site: <http://www.lungcanceronline.org/>

Lungevity Foundation Nonprofit organisation - dedicated to supporting those who have been diagnosed with lung cancer and their family members and caregivers. Includes message board, chat, detection, lung cancer facts, glossary, news, and more – USA based

Web site: <http://www.lungevity.org/>

OncoLink: Lung Cancer - includes information about different types of lung cancers, mesothelioma, and more, including treatment information, coping with cancer, clinical trials, and more – USA based

Web site: <http://www.oncolink.upenn.edu/>

Women Against Lung Cancer (WALC) - Nonprofit organisation with a mission to decrease deaths due to lung cancer, and help patients live longer and better, through research, awareness, and advocacy – USA based

Web site: <http://www.womenagainstlungcancer.org>

Appendix 3

Patient and facilitator questionnaire abstract – due for oral presentation at Australian Lung Cancer Conference, Gold Coast, August 2008

What should a support program for patients with lung cancer look like?: Differing attitudes of patients and support group facilitators

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Background and Aims: Patients with lung cancer have higher levels of unmet need for psychosocial support than those with other cancer types. However, uptake of existing support programs by lung cancer patients is low. We aimed to explore this issue by seeking the views of both lung cancer patients and existing support group facilitators. **Methods:** Surveys of a convenience sample of 100 lung cancer patients, and all support group facilitators registered with Cancer Council Victoria (n=147) was performed. Respondents were asked about preferred content, location, running and potential barriers to attendance of a support program for lung cancer.

Results: 53% of facilitators responded (n=75), 35% of whom had experience of a lung cancer patient (n<5) attend their group. Facilitators were health professionals (42%), cancer survivors (35%) and volunteers (23%), with 51% having facilitator training. 53% of patients reported willingness to attend a support program that suited their needs, although only 12% had previously attended a group. Both patients and facilitators agreed that any group should be small with important content including information about lung cancer treatments, side-effects and self-care strategies. Facilitators preferred a program run in a community hall, led by a cancer survivor, with predominant focus on social and emotional support. In contrast, patients preferred a program run in a hospital, led by a health professional, with predominant focus on treatment and disease issues. Both patients and facilitators agreed that common barriers to attendance were feeling unwell, not wanting to travel, parking and transport, and not wanting to talk about their lung cancer or participate in a group.

Conclusions: The disparities in the views of patients and facilitators about the preferred location, type of facilitator and content of a support program may in part explain the poor uptake of existing support programs by lung cancer patients, and should be considered in the design of future programs.

Appendix 4 Lung Cancer Support Pilot Program

Session 1 – Facilitator x2

Introduction to Program – (using -Session 1 of Living with Cancer Education Program)

1. Aims of Program
2. Get to know each other
3. Discussion on what people want to gain from program

Aims of Program

- Increase knowledge of lung cancer and its treatment
- Encourage discussion within a safe setting
- Learn from each other
- Increase coping skills
- Discuss common concerns

Establishing group rules

Housekeeping and group rules – short discussion around: confidentiality, respecting views of others, participation, flexibility of content, start and finishing time, tea breaks, bathroom facilities

Overview of Session 1

- Meet each other
- Your expectations
- Understanding lung cancer and lung cancer treatments

Meeting each other

- short “getting to know each other” activity

Your expectations

- discussion on what people would like to gain from program – patient expectation

Tea Break

What is Lung Cancer and Information about available lung cancer treatments?

Guest Speaker – Medical Oncologist

45 minute presentation and discussion with medical oncologist – time allowed for questions after presentation.

Tools - Power Point presentation

Resource packs to be given to participants after session 1

- Booklet – Lung Cancer

Session 2 – Facilitator x1

Side effects and symptoms of treatment – management strategies

Guest Speaker - Medical Oncologist

45 minute presentation and discussion with medical oncologist – time allowed for questions and discussion throughout presentation.

Tools - Power Point presentation

Tea break

Managing side effects of cancer – management strategies

The Role of Palliative Care

Guest Speaker - Lung Cancer Nurse Coordinator - PMCC

45 minute presentation and discussion with Lung Cancer Nurse co-ordinator – time allowed for questions and discussion throughout presentation.

Tools - Power Point presentation

Resource packs to be given to participants after session 2

- Booklet - Coping with chemotherapy
- Booklet - Coping with radiotherapy
- Leaflet - Coping with breathlessness
- Leaflet - Coping with fatigue
- Leaflet - Common Pain
- Leaflet - Lung Cancer Foundation

Session 3 – Facilitator x2

Allied Health Session

Guest Speakers

- *Dietician PMCC*
- *Physiotherapist PMCC*
- *Occupational Therapist PMCC*

General overview of what Allied Health Services provide and how to access these services

Occupational Therapist to provide small relaxation session

Tea Break

Self-Care Strategies Communication and Relationships

Discuss with group around strategies for coping with cancer. Participants to discuss what others in the group have found helpful.

Discuss some communication strategies that can be helpful when talking about your cancer with both health professionals and family/friends.

Tools - Power Point presentation – Coping with Cancer and Communication Skills

Resource packs to be given to participants after session 3

- Booklet – Cancer Services 2008
- Booklet – Life with Cancer
- Leaflet- Learning to relax
- Leaflet - Support and information sessions
- Leaflet - Telephone and Internet Support Groups

Session 4 – Facilitator x1 and Financial Advisor

Financial and Legal Issues

Guest Speaker – Financial Advisor

30 minute presentation and discussion with Financial Advisor – time allowed for questions and discussion throughout presentation.

Resource packs to be given to participants after session 4

- Financial Advice package from Wealth advisors

Tea break

Summary of what has been covered in the 4 sessions